**Commentary by carers on the present situation**

1. **Summary of issues / concerns raised by 31 carers of people with a learning disability at a specially convened meeting at Northorpe Barn on Tuesday 24th April 2018 in response to the Kirklees adult Social Care Offer**

* **Social work team and practice**

1. Lack of continuity

* Major concern about lack of available social workers, resulting in a lack of continuity, having to tell your story time and time again
* A team of static, well-skilled, consistent social workers would be a major step forward
* Cases are closed as soon as a task is completed, and any new request for help will invariably result in a new social worker being involved – so continuity is nil.

1. Lack of responsiveness

* Social work teams are unresponsive, and fail to respond to emergencies
* Carers need the reassurance of an open door when it is needed
* In terms of overall provision, why does the Council continue to press for single flats, when this does not reflect what people need and want? Flats bring isolation for many people, and settings with ‘connections’ between residents are much preferred.

1. Delays in allocation and action

* Long delays are routine in getting a social worker allocated, let alone in getting things implemented.

1. Reviews

* Reviews very rarely happen
* Carers collude with this sometimes, because for them reviews raise the prospect of cuts in support
* People with learning disabilities can find change traumatic, so changes in support need to be explained and implemented sensitively
* It is common to experience long delays in getting changes that have been agreed in reviews implemented. How long is it fair to have to wait, particularly when increases in support have been agreed as necessary?

1. Same social worker for particular settings

* In some settings (eg supported living) different social workers are allocated for each individual resident. Not only is this an inefficient use of resources, it makes it impossible to manage shared packages which are to the benefit of all those involved, and which save the Council money, too.

1. Carers assessments

* Carers assessments are not always mentioned as a right (and the forms are not helpful)
* **Impact of reducing resources/ shrinking budget**
* The capacity for genuine choices in support is reducing all the time as available money reduces, and this will get worse as rationing becomes inevitable. An over-optimistic presentation of the Social Care Offer that ignores this is not helpful, because carers know it is unrealistic.
* **Direct payments**

1. Employment of family members

* The employment of family members can be hugely positive both for the learning-disabled person (because they are being supported by somebody they trust and feel safe with) and for a direct payments budget, because on-costs are minimal

1. Carers subsidising direct payments

* Some carers are so concerned about accounting for direct payments expenditure, and the risk of overspending, that they subsidise the budget – only to find that there is money left over that they then cannot claim against because it is clawed back as ‘surplus’

1. Barriers to some forms of expenditure

– People with very complex needs may have limited choices for respite provision – and there are times when a booked place becomes unavailable because of an emergency. So the individual may end up trying several times to spend their allocation for respite, but unable to do so. This can then be seen as budget that is not required.

* Some people use direct payments – appropriately – to buy broadband or phone connections. However, Companies supplying this need an account holder (very often a home-owner) and if carers take this role, they struggle to be able to claim the direct payments for their intended use, because the arrangement is not in the name of the learning-disabled person
* The prepayment cards for direct payments don’t seem to allow for payment of taxis – so the carer can end up paying, and then struggling to get the money back

1. Claw back of unspent direct payment budgets

* It is vital that carers are informed that money is going to be clawed back before it happens. Otherwise careful and considered planning can be rendered useless.
* Companies that act on behalf of direct-debit budget holders are too quick to return money to the Council without checking with carers
* **Health Service contributions**
* NHS are routinely cost-shifting, and removing their contributions to support for people with complex health needs as well as learning disabilities. Often this happens without people being informed, and usually in their absence.
* **Broader points**

1. Meaning of ‘independence’

* In key Government documents ‘independence’ means being entirely self-sufficient. For people with learning disabilities, ‘ independence’ is something that you achieve because you have the support to do so. Can the Council confirm that its view of independence is that it is supported independence?

1. Key principles

* Fairness and consistency are the key
* ‘A strength-based approach’ is seen as code for a means of cutting support
* Four key principles should underpin the future – **Clarity** (use of language that says what you mean), **Communication** (talk to people and listen), **Continuity** (a vital element for all those involved, but rarely delivered), and **Consistency** (social workers not giving different messages and inconsistent outcomes from assessments and reviews)

1. Honesty about what is at risk

* In introducing this new Offer in a context of extreme budget pressures, the Council must have ideas about how it will help to contribute to savings. Carers would be far happier to know what areas of support are at risk, so that they can consider how to deal with the impact.

1. Planning for the future

* If the Council is aware of the massive growth in demand that is coming, what plans are in place for an increase in resources to deal with this?

1. **Summary of issues / concerns raised by a further 10 carers of people with a learning disability who met on 1st May 2018 to round off and refine the list of concerns / issues raised in the larger meeting**

**Broader points**

* If the Council is concentrating its reduced funds on those who most need them, then there will be people with learning disabilities who will not be supported in future, and yet may be unable to find sources of support from elsewhere, because there are no resources developed in their community. What will happen to them?
* Could reductions in support be introduced incrementally to minimize shock waves and give people time to adjust – particularly where carers are older and have more limited resources and energy?

**Direct Payments**

* In order to ensure that the use of direct payments results in an expanded range of provision, but one which is safe and conforms to high standards, could the Council introduce a set of criteria or a list of approved independent suppliers to assist those who are selecting their support? Feedback from current users of service would be an important element in any mechanism.

**The RAS and the assessment process**

* Whilst there is reference to the fact that the Resource Allocation System needs to change, there is no attempt to describe what that will mean, and how it will be different.
* The assessment process is left equally vague. Yet this is the key process by which people will apply for Council support. What influence will people be offered when any new process is devised, to ensure that it is user-friendly as well as fit for purpose?
* In drawing up personal budgets, how will the Council determine realistic costs for different levels of support? What if the amount you’re allowed doesn’t cover the cost of actual provision?
* Many Councils use Funding Panels to finalise what is offered – but these were only ever intended in the Care Act to be concerned with large or complex care packages. There is concern that they can become a hidden rationing device which subverts social work assessments of the care that is needed. What are the intentions locally?

**The biggest issue**

* In the introduction to the questionnaire, in ‘What are we consulting about?’ it is made clear that the need to save money and spend it carefully is a significant driver for this Social Care Offer.
* However, it was the unanimous view that, although we wished to, we could not attempt to respond on that issue, because the questionnaire was so restrictive in respect of it, and was devised only to lead to a preferred result – not to engage in consultation about it.
* Carers are not fools, and are not unrealistic. We know that the budget situation is such that cuts in support are inevitable. We could list areas which we suspect are vulnerable to being cut. Yet we were told that there was no list, and we were encouraged to think that this exercise could result in some people getting more support rather than less.
* **We feel strongly that the appropriate way forward on this is to identify areas which are under consideration to be cut, and to seek solutions together through a genuine attempt at consultation – not to be asked to collude with a game in which the uncomfortable truth is disguised. Some ways forward are relatively easier to cope with than others – and we could work together to minimize the pain whilst still recognizing the reality of cuts.**
* If it is an aim of this exercise that arrangements can be put in place that would assist carers to continue caring for longer, then the list of concerns listed above (some of which would cost little or nothing to address) is significant.
* The result of cuts in support could, in fact, be much higher expenditure as care arrangements break down – so an honest exchange is vital. That is why we are so concerned that the consultation on this significant area is not honest and gives no space for a genuine discussion.

**Submitted by Carers Sub-group of the Learning Disability Partnership Board**

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**5th May 2018**